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Singlehood and partnerships in healthy people and childhood cancer survivors

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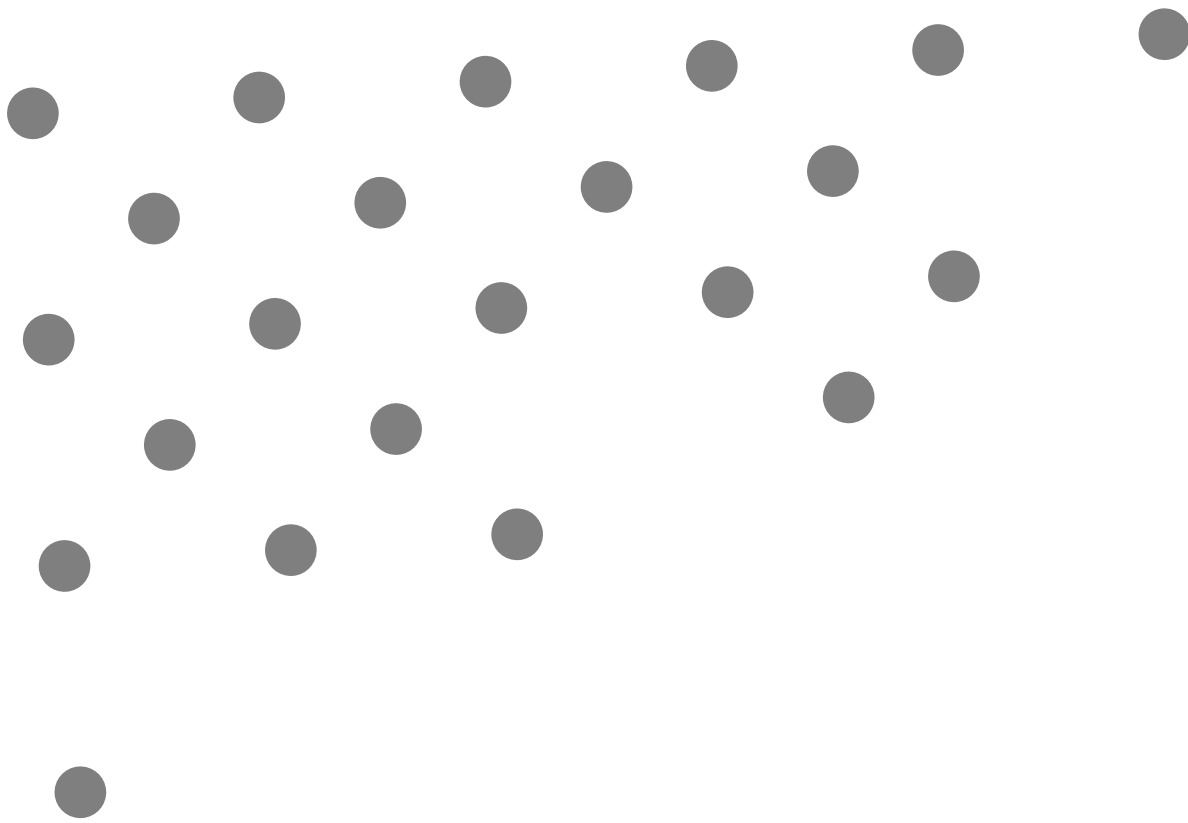
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Chapter 2:

A Scientific Introduction

In your thirst of knowledge, be sure not to drown in all the information.
(Anthony J. D'Angelo)

Adverse experiences throughout childhood can be harmful for a person's whole life. On the contrary, such experiences may also make (still growing) children stronger and braver than they could have ever been without having had them. Surviving childhood cancer might be such an adverse childhood experience that could lead people developing in both directions. During treatment, children encounter different doctors and nurses, i.e. people who are complete strangers to them. They are away from their parents, their secure environment, their friends, and they have to endure painful and long treatment regimes. All of this could have (detrimental but maybe also positive) effects on how they shape interpersonal, and specifically romantic relationships later in life. Survivors may be less open to close relationships, or conversely they may feel very mature and handle interpersonal relationships with great care and appreciation. Overall, this is something we do not fully understand yet.

Getting cancer at any time from birth to late adolescence (i.e. until age 18) can surely have diverse effects, where not only the timing, but also other factors can play a crucial role. For example, a toddler being diagnosed with leukemia and awaiting a bone marrow transplant is probably experiencing his/ her cancer in a total different way than a 15 year old boy with testicular cancer undergoing chemotherapy. However, when they are emerging into adulthood, they may be faced with **the same problems**:

They may have physical problems, such as an overall reduced physical functioning, reduced heart-lung capacities, infertility, and others (e.g., [1-3]). They may also carry visible reminders of their former disease on their bodies, such as scars or amputations. This can make interactions with others more difficult, especially when it comes to romantic and sexual relationships; potentially making survivors more insecure, hesitant, or less experienced than healthy people.

Survivors with different cancer histories may also be faced with **the same questions** in emerging and young adulthood when it comes to romantic and sexual relationships:

How will others react to their stories (and scars)?
 If they start dating, should they tell about their former disease? -and when?
 Could they better not get involved with others, because they may get relapses or new tumors?
 Can they have children and do they want to have children?

Previous research, among adults who have survived childhood cancer, has identified certain negative late effects such as worse psychological, social, emotional, educational, vocational, and sexual functioning based on comparing survivors with siblings or peers [1, 2, 4-7]. However, general conclusions based on previous research can hardly be drawn due to methodological issues [1, 2, 4-7]. Furthermore, qualitative studies have suggested positive consequences of surviving childhood cancer, such as positive emotions, attitudes, and beliefs about life, broader perspectives, personal maturation and confidence, or closer relationships [4, 8-12].

Given a potentially different attitude towards life, childhood cancer survivors may indeed approach and handle romantic relationships in a different way. This might be reflected in a frequently reported lower marriage rate in childhood cancer survivors compared to siblings or peers [13-26]. However, some studies also reported no differences [27-31], or suggested a delay in marriage to a later age in survivors [32]. Nonetheless, these frequencies do not tell us anything about the well-being of childhood cancer survivors, and how they feel about either being married/ in a relationship or being single. We do not know whether survivors want to marry and whether they are unhappy singles. More importantly, we do not know whether the cancer experience is ‘the’ reason for this finding.

We could identify four (qualitative) studies that specifically showed how a childhood cancer history can influence adult romantic relationships. Gray and colleagues [33] found two extremes that were reported by survivors: trying to be very close to a partner or keeping people at distance as a consequence of their treatment experience. Survivors reported being serious about relationships leading them to not date casually and get less easily involved with others. Quinn and colleagues [34] identified internal barriers that influenced romantic relationships; such as survivors being worried that dating partners feel sorry for them or pity them; or that survivors base decisions on whether to continue dating a person or not on the other person’s reaction to their scars. Some survivors in a study by Holmes and Holmes [35] saw their previous disease as hindrance to marriage, and Thompson and colleagues [36] found several concerns that survivors had regarding romantic relationships, such as hesitation to disclose their cancer experience (in great detail), the partner’s reactions, possible infertility, and physical intimacy.

Hence, letting someone close (emotionally and physically) seems to be influenced by various personal and interpersonal factors. In turn, attitudes towards the self and sexuality can contribute to general well-being. This is, of course, not only relevant in the context of cancer. Any person -healthy or not- is confronted with these issues when it comes to sexual and romantic relationships.

Overall Scope

Intimate relationships and a healthy sexuality are central aspects of human adult life, and vital for general well-being. The aim of this project is to examine whether partnerships, singlehood, sexuality, and the satisfaction with these aspects are impaired in young adult survivors of childhood cancer (compared to healthy people). We wanted to further evaluate whether self-perceptual factors play a role in influencing these aspects.

In order to test the validity of associations, we first studied our proposed factors and outcomes in a healthy population, before comparing survivors to peers without a cancer history. While preparing our studies, we had identified several issues and problems in the general psychological and childhood cancer survivor literature, which were addressed and incorporated in this project (described below).

Overview of the issues addressed in this dissertation

	addressed in:	healthy people	cancer survivors
issue	in chapter:		
<u>general issues</u>			
# 1	neglect of single people	3	
# 2	relationship status satisfaction and well-being	3	
# 3	sex and relationship status satisfaction	4	
# 4	self-perception and relationship status satisfaction	4	
<u>turning to cancer</u>			
# 5	body image and cancer survivors		5
# 6	combining several issues in childhood cancer survivors and healthy peers	6	6
# 7	consequences of cancer on a specific life phase		7

General issues

Issue #1: *Neglect of Single People*

Singlehood is a largely neglected topic in psychological research about sexuality and (sexual) satisfaction [37], while the literature is flooded by studies investigating couples and their relationship/ marital and sexual satisfaction. How is this imbalance possible, when the numbers of single households and divorce rates are rising?

A general part of the human life cycle is the formation of intimate relationships. However, whether these intimate relationships are casual, long-lasting, uncommitted, resulting in marriage or divorce is subject to change over time within people, but also in society as the forms of dating and relationships have changed over the past decades and became more open [38]. Together with this, lived sexuality has changed [39]. One-night stands and uncommitted sexual relationships are more accepted nowadays and sex does not necessarily need a marriage certificate anymore.

Due to these changes, the consideration of single people in research about relationship status and sexual satisfaction becomes increasingly important, but there has been only one effort to develop an instrument measuring the satisfaction with singlehood [40]. This instrument was meant to measure satisfaction with singlehood, as well as whether people are single by choice, and their present and future preferences concerning their single status. Given its broader scope of not only looking at satisfaction, the wording of some items was biased towards negative feelings about singlehood (e.g., lonely, frustrated, incomplete, or bothered [40]). We wanted to avoid such items in our study. We concluded that there was no appropriate instrument to measure single people's satisfaction with their singlehood, and more importantly, there was no instrument which could be used to simultaneously measure single and partnered people's satisfaction with their respective status. We considered this utterly important in order to be able to compare both partnered and single people, and in order to conduct studies without knowing people's relationship status beforehand. Therefore, the first step in this project was the development of the Satisfaction with Relationship Status Scale (ReSta), an analog scale to measure people's *relationship status satisfaction*, also referred to as status satisfaction (see Chapter 3).

Issue #2: *Relationship Status Satisfaction and Well-Being*

Previous research highlighted that partnered individuals are doing better than single people in terms of reporting higher levels of well-being. Nevertheless, there are numerous indications underlining that other factors play a vital role in well-being (see Chapter 3). In line with this, we argued that a simple dichotomization into single and partnered people is little informative and suggested investigating people's actual satisfaction with their respective relationship status instead. We proposed that status satisfaction, as measured by ReSta, is an important predictor for general well-being (i.e. life satisfaction and distress), beyond relationship status itself (see Chapter 3).

Issue #3: *Sex and Relationship Status Satisfaction*

After examining status satisfaction as a predictor for well-being, we wanted to turn the perspective to factors that potentially influence how satisfied people are with their respective relationship status (see Chapter 4). The first factor included in this dissertation was sexual satisfaction. A close connection between sexual and *marital* satisfaction seems apparent (e.g. [41-44]). However, since sexual well-being is any human's right [45]; and due to a changed society and more open sexuality [38], the consideration of single people's sexual satisfaction became important and discussable too. Therefore, we hypothesized that sexual satisfaction is not only an aspect influencing partnered people's status satisfaction, but also single people's satisfaction with their singlehood.

Issue #4: *Self-Perception and Relationship Status Satisfaction*

People's thoughts about themselves shape how they interact with others. Intimate relationships require the interaction with others and hence, a person's self-perception could highly influence whether people get involved in sexual and intimate relationships and how satisfied they are sexually. In turn, this potentially influences how satisfied they are with either being in a relationship or being single. In this dissertation, we focused on two self-perceptual factors, self-esteem and body image, for two reasons. First, they are related, and second, they are thought to be crucial factors when it comes to sexuality, which is expected to strongly influence status satisfaction (see Chapter 4).

Turning to Cancer

Issue #5: *Body Image in Cancer Survivors*

Before turning to long-term childhood cancer survivors, we wanted to focus on one of the self-perceptual factors, namely body image, in all types of cancer survivors. We aimed to review the previous literature on whether body image is impaired in cancer survivors, because one might assume that cancer and its treatment dramatically impair the body in various ways. However, an overview of the previous literature was missing. In order to examine whether body image is likely to be altered due to cancer, we decided to focus on case-control studies, comparing cancer survivors with healthy controls (see Chapter 5).

Issue #6: *Combining Several Issues in Childhood Cancer Survivors and Healthy Peers*

As indicated before, romantic relationships and sexual intimacy in relation to self-perception are already very complex and probably complicated to understand in healthy people. However, it might be even more important to examine whether (and to what extent) long-term childhood cancer survivors struggle with these issues for several reasons (see below). Therefore, we combined almost all of the previously addressed issues in order to thoroughly investigate childhood cancer survivors while comparing them to healthy peers; focusing on both single and partnered people (#1) and their status satisfaction in relation to their sexual satisfaction (#3) and self-perception (#4, where we specifically focused on body image, #5).

The body is important for a healthy sexuality. However, childhood cancer survivors may have a more negative body image due to their cancer treatment. They might be left with scars, stretch marks, or amputations. Therefore, they may perceive their bodies as more negative, not only regarding its appearance, but also functioning. In addition, childhood cancer survivors may feel less connected to their bodies as, for example, pain and nausea led them to turn away from bodily signs. They may have never learned that their bodies can also bring them pleasure. Hence, they may also experience a positive physical state of arousal (i.e. sex) as less enjoyable.

In turn, a more problematic body and sexuality could lead survivors to be less satisfied with their current relationship status. Survivors may encounter problems with letting people get close to them, physically but maybe also emotionally. Therefore, they may have less sexual experiences and/ or they may be in relationships less often than healthy people.

In short, there might be certain self-perceptual and intimacy issues that turn out to be more complicated for childhood cancer survivors than for healthy people. Therefore, we investigated and compared survivors and healthy controls on body issues (i.e. body image and body dissociation), sexual satisfaction, and the satisfaction with their relationship status (see Chapter 6).

Issue #7: *Consequences of Cancer on a Specific Life Phase*

Eventually, we zoomed in on a specific group of childhood cancer survivors: those who were diagnosed during adolescence and who were currently 10 years after diagnosis. We took a more explorative approach by analyzing interviews of these survivors. All survivors were aged 23-29 and had reached a new phase in life: emerging and young adulthood. A time marked by numerous changes and instability, ranging from moving out of the parental home, starting to study or work, engaging in more serious relationships or entering marriage, and starting (to plan) an own family [46]. A former cancer diagnosis might have a specific impact on this life phase, since it entails numerous developmental tasks, which might be problematic for survivors. The survivors in this study were followed longitudinally up to 10 years, and they were explicitly asked whether they experienced any negative and/ or any positive consequences due to their former cancer disease. The interviews were not specifically intended to ask survivors about the topics included in this dissertation thus far (i.e. self-perception, sexual and status satisfaction), making us all the more curious whether survivors would report any negative or positive aspects related to these topics by themselves (see Chapter 7).

In short, the issues described above will be addressed in the following chapters of this dissertation. We investigated healthy people first, in order to address issue #1, #2, #3, and #4, before turning to cancer survivors and addressing almost all issues in both healthy people and cancer survivors; before eventually zooming on a specific group of adolescent cancer survivors 10 years after diagnosis.

As outlined, the overall scope of this project was to examine whether singlehood, partnerships, sexuality, and specifically the satisfaction with these aspects might be impaired in young adults, who were diagnosed with cancer during childhood and adolescence; taking self-perceptual factors into account.

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